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Burden experienced by families of Patients with schizophrenia and its related factors

By

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Abstract

Aim: This study aimed to assess the burden experienced by the caregiver of patients with Schizophrenia, and evaluate its correlation with some demographic characteristics of patients, their caregivers, and the level of expressed emotion in the family.

Methods: This descriptive-analytic study was conducted on 172 schizophrenic patients and their primary caregivers selected from the outpatient clinic of a mental hospital in Tehran, Iran using convenience sampling. Caregivers were evaluated with Zarit Burden Interview and Family Questionnaire to assess the burden experienced by the caregivers and the level of expressed emotion in the family, respectively. Data were analyzed using Mann-Whitney, Kruskal-Wallis, and Spearman's tests.

Results: The level of burden experienced by the majority of primary caregivers was moderate to severe. The scores obtained in the subscales of emotional over-involvement and critical comments were higher than the cutoff point in 51.7% and 64.5% of caregivers respectively. The results showed that the scores obtained in the two subscales of family questionnaire had a significant, direct correlation with the burden experienced by the caregivers. The level of burden experienced by the caregivers was significantly different between the subgroups of age and marital status of the caregivers, and gender, occupational status and marital status of the patients. Number of family members, home ownership status, time spent by the caregiver with the patient daily, level of family

income and duration of disorder significantly affected the level of burden experienced by the caregiver.

Conclusion: Based on the results, some demographic factors of the primary caregivers, patients and their family significantly affect the burden experienced by the primary caregivers. Most of the families of patients have high expressed emotions and a significant, direct association exists between the expressed emotions and the burden experienced.

Key words: Schizophrenia, burden, caregiver, expressed emotion, demographic characteristics.

Resumo

Objetivo: Este estudo teve como objetivo avaliar a *carga* dos cuidadores de doentes com Esquizofrenia e avaliar a correlação com determinadas características demográficas dos doentes e dos cuidadores, assim como com o nível de emoção expressa na família.

Métodos: Este estudo descritivo-analítico foi realizado em 172 doentes com Esquizofrenia e seus cuidadores primários, que foram selecionados em ambulatório, a partir da consulta externa do Hospital Psiquiátrico em Teerão, no Irão, mediante uma amostra de conveniência.

Os cuidadores foram entrevistados utilizando as escalas *Zarit Burden Interview* e *Family Questionnaire,* de forma a avaliar a sobrecarga sentida pelos cuidadores e o nível de emoção expressa na família, respectivamente. Os dados foram analisados por meio de testes de Mann-Whitney, Kruskal-Wallis, e Spearman.

Resultados: O nível de sobrecarga vivenciada pela maioria dos cuidadores primários foi moderada a grave. A pontuação obtida nas sub-escalas de comentários emocionais, envolvimento excessivo e comentários críticos foram maiores do que o ponto de corte em 51,7% e 64,5% dos cuidadores, respectivamente. Os resultados mostraram que as pontuações obtidas nas duas subescalas do questionário família tinham uma correlação significativa e direta com a carga experimentada pelos cuidadores. O nível de carga experimentada pelos cuidadores foi significativamente diferente entre os grupos de idade e estado civil dos cuidadores, e género, status ocupacional e estado civil dos doentes. O número de membros da família, as condições

de alojamento, o tempo gasto pelo cuidador com o paciente diariamente, o nível de renda familiar e a duração da doença afetaram significativamente o nível de carga experimentada pelo cuidador. **Conclusão:** Com base nos resultados, alguns fatores demográficos dos cuidadores, pacientes e seus familiares afetam significativamente a carga experimentada pelos cuidadores primários. A maioria das famílias dos pacientes têm alto nível de emoção expressa e existe uma significativa associação direta entre as emoções expressas e a carga experimentada.

Palavras-chave: Esquizofrenia, carga, cuidador, expressa emoção, demografia

Resumen

Objetivo: Este estudio tuvo como objetivo evaluar la carga experimentada por el cuidador de pacientes con Esquizofrenia y evaluar su correlación con algunas características demográficas de los pacientes, sus cuidadores, y el nivel de emoción expresada en la familia.

Métodos: Este estudio descriptivo-analítico se realizó en 172 pacientes esquizofrénicos y sus cuidadores primarios seleccionados de la consulta externa de un hospital psiquiátrico en Teherán, Irán, mediante un muestreo de conveniencia. Los cuidadores fueron evaluados con el Inventario Zarit de Carga y el Cuestionario de Familia para evaluar la carga experimentada por los cuidadores y el nivel de emoción expresada en la familia, respectivamente. Los datos fueron analizados utilizando las pruebas de Mann-Whitney, Kruskal-Wallis, y Spearman.

Resultados: El nivel de carga experimentada por la mayoría de los cuidadores primarios fue de moderada a severa. Las puntuaciones obtenidas en las subescalas de sobre-involucramiento emocional y comentarios críticos fueron más altos que el punto de corte en el 51,7% y el 64,5% de los cuidadores, respectivamente. Los resultados mostraron que las puntuaciones obtenidas en las dos subescalas del cuestionario familiar tuvieron una correlación significativa y directa con la carga experimentada por los cuidadores. El nivel de carga experimentado por los cuidadores fue significativamente diferente entre los subgrupos de edad y estado civil de los cuidadores, y el género, situación laboral y estado civil de los pacientes. El número de miembros de la familia, el estado de propiedad de la vivienda,

el tiempo diario dedicado por el cuidador para estar con el paciente, el nivel de ingresos de la familia y la duración del trastorno afectáran significativamente el nivel de carga experimentada por el cuidador.

Conclusión: En base a los resultados, algunos de los factores demográficos de los cuidadores primarios, de los pacientes y de sus familias afectan de manera significativa la carga experimentada por los cuidadores primarios. La mayoría de las familias de los pacientes tienen alto nivel de emociones expresadas y existe una asociación significativa y directa entre las emociones expresadas y la carga experimentada.
Palabras clave: Esquizofrenia, carga, cuidador, emoción expresada, características demográficas.

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Introduction

An estimated 50 to 80% of persons with schizophrenia and related psychotic disorders live with or have regular contact with a family caregiver (1, 2). These caregivers report high levels of burden related to caring for their family members (3). Demands of caregiving include paying for psychiatric treatment, supervision of a mentally ill family member, dealing with societal stigma associated with mental illness, and emotional distress that may result from symptoms of a family member's illness. The level of burden experienced by caregivers of persons with schizophrenia is equivalent to that of caregivers of persons with other neurological (e.g., Alzheimer's disease, mental retardation) and physical (e.g., diabetes, cancer) disorders (4, 5). As a result of the high proportion of family members providing care to persons with schizophrenia and the high rates of burden reported by these caregivers, researchers have attempted to identify predictors of family burden and to design family interventions that reduce the negative consequences of caring for persons with schizophrenia. Over the past two decades the deinstitutionalization movement has shifted the primary locus of care from psychiatric hospitals to community mental health centers. However, the funds for professional community resources have been limited and families of the seriously mentally ill have been asked to take increasing responsibility for practical help and emotional support for patients living in the community (6). In Iran this process has been particularly rapid. It has been estimated that more than 50% of patients

with schizophrenia discharged from psychiatric hospitals return to live with family members (7).

There is considerable research evidence on the high levels of financial burden, strain and distress related to caring for an ill family member (8-10). Families incur costs in terms of psychological strain, social isolation and other practical burdens (11-13). Emotional strains, financial difficulties and social stigma taken together are referred to as family burden. Hoening and Hamilton (1965) attempted to distinguish between objective and subjective burden (14). The objective burden included the effects on finance, health, routine and leisure of the family, while the subjective burden was the perception of the adverse effects of illness.

In the family that one of the members gets hurt, personal needs may be changed into increasing needs to the family time and sources (15) and may have terrible effects on the family (16). Family members, spouses and partners, and friends of patients are obviously impacted by a patient's illness. While these important persons spend far more time with patients than either physicians or the mental health professionals who provide care, family members are frequently, albeit unintentionally, left out as important players in the care and management of persons who are chronically ill. Such a patient puts all other members in a sorrowful condition (17).

Expressed emotion (EE), is a measure of the family environment that is based on how the relatives of a psychiatric patient spontaneously talk about the patient (18). Theoretically, a high level of EE in the home can worsen the prognosis in patients with mental illness, or act as a potential risk factor for family burden (19). Families of patients with schizophrenia

are rated as ‘High EE’ if they are critical (negative comments about the behavior or characteristics of the patient), hostile (very general criticism or rejection of the patient) or emotionally over involved (EOI) (exaggerated emotional response, over-intrusive or self-sacrificing behavior and/or over-identification with the patient) (20).

Statement of the problem

It is estimated that more than 14,000 psychiatric beds are needed to provide short-term hospitalization services in Iran, which is approximately double the available beds at present.

Family members often play a vital role as caregivers in the lives of individuals with schizophrenia and other serious mental illnesses. It has been estimated across studies that 30-85% of adults with schizophrenia have a family member as a caregiver (21). The burden of people caring for a family member with mental illness is considerable. The families must sometimes cope with the stress of the patient’s disruptive symptoms, strained social relations within the family, loss of social support, diminishing opportunities for leisure, and deteriorating finances. Furthermore, family members often have mixed feelings, such as sorrow, anger, guilt, and shame. All these burdens severely tax the family members coping and adjustment abilities and the strain frequently results in anxiety, guilt, and depression (16).

In Iran, a significant number of patients live with their extended families. Family members are emotionally close, expressive and most of their time is spent collectively with other family members and relatives. There are very

limited community-based mental health services, halfway houses or alternative living facilities. The resources to support families are beginning to develop, but are very limited in the face of the huge demand. Therefore, individual differentiation is different compared to Western countries. Following discharge from hospital, most of the patients must rely on family support with minimum community follow-up. Mental health services are based on a hospital-oriented approach with no community care and psychoeducational interventions are not widely used due to limited resources. Therefore, a family's ability to cope with illness becomes a critical issue (22). In spite of the great burden that is imposed on families, a study conducted in Iran revealed that most families are willing to take care of their loved ones at home. Their most pressing needs were accessibility of hospital beds during the time of relapse and the provision of rehabilitation and educational services (23).

A study in Iran showed a high Expressed Emotion (EE) rate of 60% in the families of patients with schizophrenia (22). The results were close to the other EE studies in Western countries, with a high EE range of 40 to 74% and different to the study in India with a high EE rate of 23% (24). Therefore, as stated by Bhugra and McKenzie (2003), normative cultural data on EE in the general population should be available before clinicians can assess the prevalence and effects of high EE among the families of patients with psychiatric disorders (25).

Navidian and Bahari (2008) studied the burden experienced by family caregivers of patients with mental disorders in Iran. They concluded that

the burden can reduce the quality of care giving and can also endanger the mental health and physical health of caregiver. Therefore, to reduce the rate of such burdens, some interventions including home visit, education, family therapy and group therapy seem necessary to be applied so that the quality of care giving gets better and the physical and mental health of care givers as hidden patients improves (7).

The relationships of burden and socio-demographic variables have also been studied. Martin-Yellowe (1992) found that rural families of the schizophrenic patients experienced significantly more financial burden than urban families (26). Stress level was higher among the family members of male patients (27). The relatives of patients with schizophrenia reported more social deficits for male patients in comparison with female ones (28). In a study Trivedi et al. (2003) found that the parents and siblings of schizophrenic patients experienced more burdens in comparison to spouses. They also stated that young relatives and those having the age range of above 45 experienced more burden than the middle age group relatives (29). There is a positive correlation of family burden and duration of illness (30). Jenkins and Schumacher (1999) contended that not only the patients' gender but also the gender of the caregivers must be considered (28).

Caregiver resources such as high active and low passive coping, as well as high social support have been repeatedly linked to low levels of burden (31, 32). These personal and social caregiver resources appear to be particularly important predictors of burden. Among caregivers of persons with

schizophrenia, Magliano et al. (1998) found that family coping strategies accounted for 56% and 47% of the variance in objective and subjective burden, respectively (33). Other authors have proposed that caregiver coping and social support may mitigate the relationship between patient stressors and family burden (34, 35).

This study mainly describes the burden experienced by families (main caregivers) of the Patients with schizophrenia and evaluates the relationship between expressed emotions, some of the demographic characteristics of the main caregiver and patient, and also the duration of the disorder with the burden that has been experienced by the caregivers.

Objectives

This study aimed at determining the burden experienced by the families of patients with schizophrenia. The specific objectives were to determine the relationship between the burden of the families and 1) expressed emotion, 2) some of the demographic characteristics of the patient and main caregiver, and 3) duration of the disorder.

Null Hypothesis (H0)

In families of patients with schizophrenia, there is not direct association between the expressed emotions and the burden experienced by main caregivers.

Methods

This is a descriptive-analytic study. The caregivers of patients with schizophrenia from the outpatient clinic of a teaching center in Tehran, Iran were enrolled in the study.

Sample size

Sample size calculation was based on the burden which had been experienced by the caregivers. The results of a study in Iran using ZBI showed that 26.4% of caregivers suffered from a mild level of burden, 60.8% had moderate of burden, and 12.8% had high burden (7). The sample size was calculated for the high burden that had the lowest frequency.

$n= z^2_{(1-\alpha/2)} \times P \times (1-P) /d^2$ where d (precise) = 0.05

$n= (1.96 \times 1.96) \times (12.8/100) \times (87.2/100)/0.0025 = 171.51$

Therefore regarding to the above calculation the sample size was 172 caregivers.

Instruments

1) **Demographic questionnaire** included some of the demographic characteristics of the patient and main caregiver such as: age, gender, educational level, marital status, occupational status … as well as duration of the disorder.
2) **The Zarit Burden Interview** (ZBI) is a widely used 22-item assessment tool for measuring caregiver's perceived burden of providing family care. It asks family caregivers about areas that may cause stress and strain such as physical, psychological, economic, and relational

problems. Items are answered on a 5-point scale ranging from (0) never to (4) always (36). Score are added to give the total score which ranges from 0 to 88, with higher scores implying greater perceived caregiver burden. Interpretation of score: 0 – 21 little or no burden, 21 – 40 mild to moderate burden, 41 – 60 moderate to severe burden, 61 – 88 severe burden. The psychometric properties of the ZBI include an acceptable inter-item reliability and convergent validity, indicated by a Cronbach's alpha of .79 and a correlation coefficient of .71 between caregiver's global evaluation and ZBI scores. A test-retest reliability of .71 and internal consistency (Cronbach's alpha= .91) also have been reported (36-38). Navidian et al. translated and modified Zarit Burden Interview based on Iranian culture standards (7). Its reliability was calculated by test-retest method (r= .94).

3) **The Family Questionnaire** (FQ) is a self-rating questionnaire (39), this was designed in Germany by Wiedemann, et al. (2002). It has 20 items and measures two sub-scales of EE (critical comment and emotional over-involvement). It has good reliability and validity. There is no need for special training to administer the questionnaire and it is not time consuming. Results of a preliminary study in Iran showed a good internal consistency. Internal consistency for the total score of the scale was 0.80, for the criticism subscale it was 0.88 and for the EOI subscale it was 0.83 (40). The cutoff point for the FQ critical comment scale was a score of 23, with a cutoff of 27 for FQ emotional over-involvement scale. In this study, the FQ was used to

measure the EE level of family members in the study. Consistent with other EE studies, the household was considered as high EE if one family member was rated as high EE (22).

Procedure

This study was approved by the Ethic Committee in Mental Health Research center, Iran University of Medical Sciences. After that the samples were selected using convenience sampling in outpatient clinic. The inclusion criteria were:

- Clinical diagnosis of schizophrenia for the patient based on the DSM-IV-TR;
- The patient lives with at least one key member of his/her family;
- No patient with organic problem and addiction

A caregiver was one who was a member of the family and had the most frequent contact with the patient, helped to support the patient financially, had most frequently been collateral in the patients' treatment and with the age of at least 15 years who was able to make a good communication.

Families of all patients were invited to a group briefing session (20 families in each session) and the objectives of the research were explained to the families. Then an informed consent was obtained from both patients and their families. If they were not interested in participating in the study, we excluded them. Families that agreed to participate in the research were enrolled. After taking informed consent, the patients and their families were assessed by demographic questionnaire (for demographic characteristics and duration of the disorder), and then the families were assessed with Zarit Burden Interview for burden of caregivers and Family

questionnaire for expressed emotion. Managing of Group briefing sessions were performed by the main researcher. In addition there was a psychologist with enough experience as assistant researcher that filled in the questionnaires and took informed consent. She was familiar with these kinds of questionnaires and also for more orientation participated in a 4-hour training workshop concerning the questionnaires.

Planned analysis

Descriptive summaries of socio-demographic characteristics of the patients and caregivers were provided for all participants. The Frequency of the caregivers was presented in the different levels of burden. The frequency of high expressed emotion for sub-scales of FQ was presented. The correlation of ZBI score with FQ (critical comment and emotional over-involvement sub-scales) and Duration of the disorder will be calculated by Spearman Test. The mean scores of ZBI between the sub-groups of demographic characteristics were compared with Mann–Whitney U test or Kruskal-Wallis Tests.

Results

This study was conducted in the Outpatient Clinic of a university affiliated mental hospital in Tehran, Iran. Understudy patients were 172 patients with schizophrenia along with their primary caregivers (n=172). Of total, 5 patients (2 female and 3 male) rejected to participate in the study.

Demographic characteristics of primary caregivers:

Of 172 participants, 129 (75%) were females and 43 (25%) were males. Of all, 141 (82%) were married, 13 (7.6%) were divorced or widowed and the remaining were single. Of the interviewees, 151 (88%) were literate; out of which, 79 (52%) had high school diploma or university education.

In terms of occupational status, 56 (32.6%) were employed, 85 (49.4%) were housewives and 8 (4.7%) were unemployed. The mean age of caregivers was 46.3±11.3 years.

In terms of home ownership status (where the patient and the caregiver resided), 135 (78.5%) owned the place. Regarding the duration of time spent by the caregiver with the patient, 86 caregivers (50%) spent less than 6 hours/day caring for the patient (Table 1).

Table 1: Demographic characteristics of the caregivers (N=172)

Characteristics	Number	Percent (%)	Cumulative percent (%)
Gender			
male	43	25	25
Female	129	75	100
Age (y)			
< 25	5	2.9	2.9
25-34	27	15.7	18.6
35-44	46	26.7	45.3
45-54	50	29.1	74.4
>55	44	25.6	100
Marital Status			
single	18	10.4	10.4
Married	141	82.0	92.4
Divorced or widowed	13	7.6	100
Occupational status			
Employed	56	32.6	32.6
Housewife	85	49.4	82.0
Student	8	4.7	86.6
Retired	15	8.7	95.3
Unemployed	8	4.7	100
Educational level			
Illiterate	21	12.2	12.2
Elementary school	24	14.0	26.2
High school	99	57.6	83.8
University	28	16.2	100

Demographic characteristics of patients:

Of 172 patients participating in the study, 100 (58.1%) were males and 72 (41.9%) were females; 95 (55.2%) were single, 46 (26.7%) were married, and 31 (18.0%) were divorced or widowed. In terms of occupational status, 48 (27.9%) were employed.

The mean age of patients was 36.8±10.2 years. Patients were mostly (37.8%) in the age range of 25-34 years. All patients were literate. Of all, 50 (29.1%) were living with their spouse and children; 111 (64.5%) were living with their parents and 11 (6.4%) were living with other family members/relatives (Table 2).

The mean duration of disease was 7.6±6.9 years; 82% of patients were sick for 10 years or less.

Table 2: Demographic characteristics of the patients (N=172)

characteristics	Number	Percent (%)	Cumulative percent (%)
Gender			
male	100	58.1	58.1
Female	72	41.9	100
Age (y)			
< 25	24	14.0	14.0
25-34	65	37.8	51.7
35-44	41	23.8	75.6
45-54	31	18.0	93.6
>55	11	6.4	100
Marital Status			
single	95	55.2	55.2
Married	46	26.7	82.0
Divorced or widowed	31	18	100
Occupational status			
Employed	48	27.9	27.9
Housewife	29	16.8	44.7
Student	9	5.2	49.9
Retired	2	1.2	51.1
Unemployment	84	48.9	100
Educational level			
Elementary school	73	42.4	42.4
High school	82	47.7	90.1
University	17	9.9	100
Duration of illness (y)			
Lesser than 2	23	13.4	13.4
2 – 5	59	34.3	47.7

5 – 10	59	34.3	82.0
More than 10	31	18.0	100

Demographic characteristics of the families:

The results showed that 105 families (61%) had a monthly income of 7,500,000 to 10,000,000 Rials; 45 families (26.2%) had a monthly income of 5,000,000 to 7,500,000 Rials and 5 families (2.9%) had a monthly income less than 2,500,000 Rials. None of the families had a monthly income over 10,000,000 Rials. The results showed that 57.6% of families had one to three members and the mean household size was more than three in 42.4% (3).

Table 3: Demographic characteristics of the families (N=172)

characteristics	Number	Percent (%)	Cumulative percent (%)
Number of family members			
1-3	99	57.6	57.6
>3	73	42.4	100
Ownership status of residential place			
Owner	135	78.5	78.5
tenant	37	21.5	100
Patient Lives with			
Spouse or children	50	29.1	29.1
Parents	111	64.5	93.6
Other relatives	11	6.4	100
The time that caregivers spend with patients/day (h)			
Lesser than 6	86	50.0	50.0
6 - 12	64	37.2	87.2
More than 12	22	12.8	100
Average income of family/ month (Rials)			

<2500000	5	2.9	2.9
2500000-5000000	17	9.9	12.8
5000000-7500000	45	26.2	39.0
7500000-10000000	105	61.0	100

The results of Zarit Burden Iterview:

The mean score of burden experienced by the primary caregivers in our study was 49.7± 13.8. Based on the interpretation of scoring of questionnaire, the results showed that the level of burden experienced by more than 70% of caregivers was higher than moderate severity. Figure 1 shows the frequency percentage of different levels of burden experienced by the caregivers in the current study.

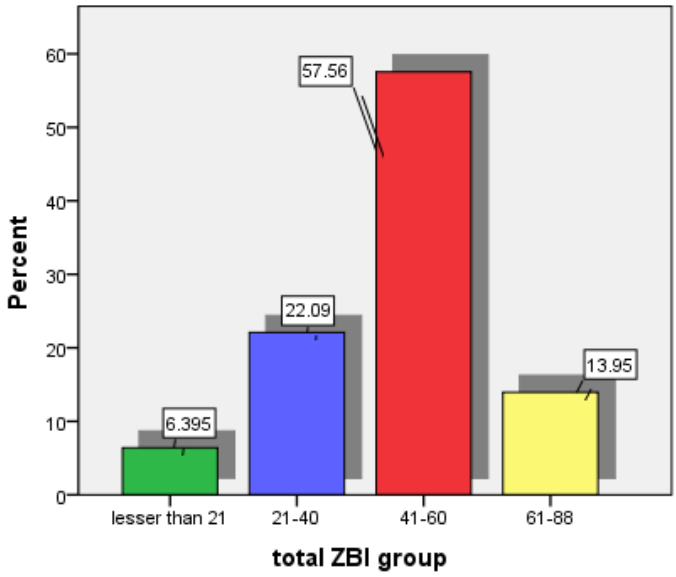

Figure 1: The frequency percentage of different levels of burden experienced by the primary caregivers

The results of family questionnaire:

The mean total score of family questionnaire gained was 51.3±9.9. The mean score was 24.5±5.5 for the subscale of critical comments and 26.7±4.8 for the emotional over-involvement subscale. The frequency percentage of caregivers with a mean score equal or above the cut-off point, based on a cut-off point of 23 for the critical comments and a cut-off point of 27 for emotional over-involvement, were 64.5% and 51.7%, respectively. (Figures 2, 3)

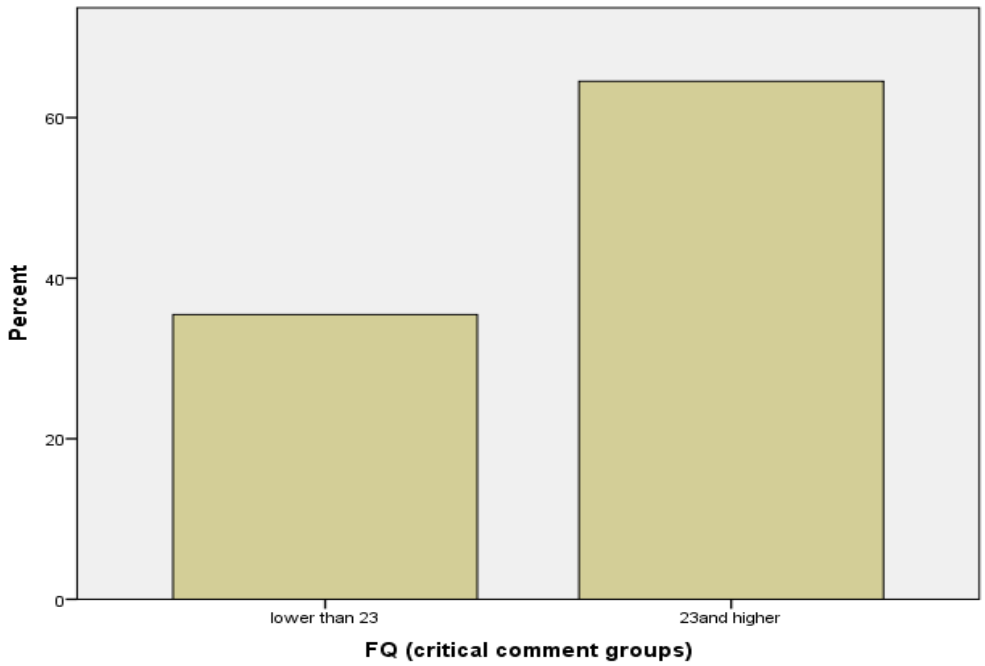

Figure 2: The frequency percentage of caregivers based on the cut-off point of 23 for critical comments subscale

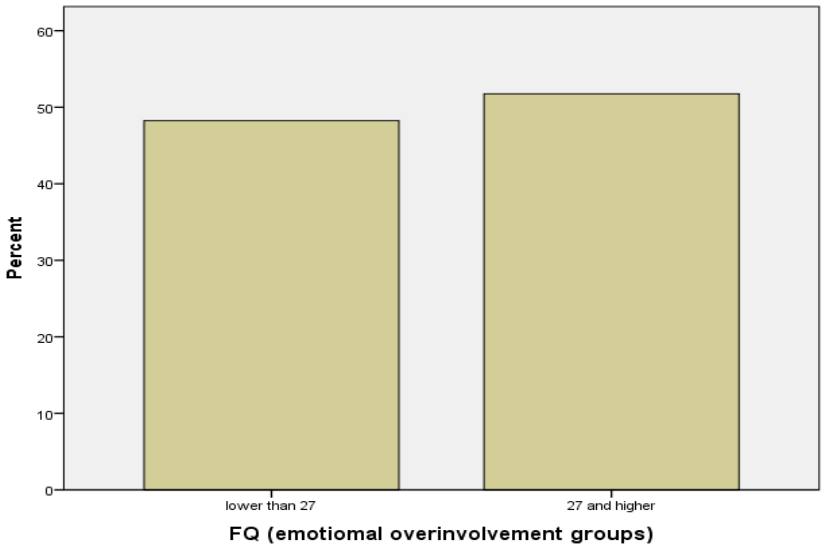

Figure 3: The frequency percentage of caregivers based on the cut-off point of 27 for emotional over-involvement subscale

The correlation of level of burden experienced by the primary caregiver and the family questionnaire score (subscales of critical comments and emotional over-involvement):

The level of burden experienced by the primary caregiver was found to be associated with the subscale score of critical comments in the family questionnaire (Figure 4). This correlation was a direct one; it means that the higher the critical comments expressed by the family, the greater the level of burden experienced by the primary caregiver ($P<0.001$, Spearman's rho: $r=0.46$).

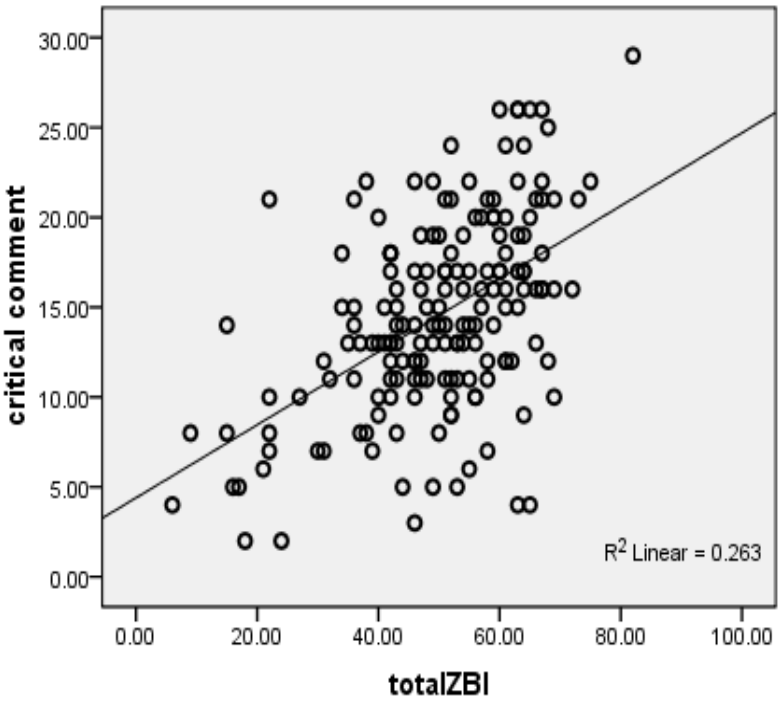

Figure 4: The diagram of correlation between the mean score of burden experienced by the caregiver and the mean subscale score of critical comments in the family questionnaire

The level of burden experienced by the primary caregiver was found to be associated with the subscale score of emotional over-involvement in the family questionnaire (Figure 5). This correlation was a direct one; it means that the higher the emotional over-involvement of the family, the greater the level of burden experienced by the primary caregiver ($P<0.001$, Spearman's rho: $r=0.38$).

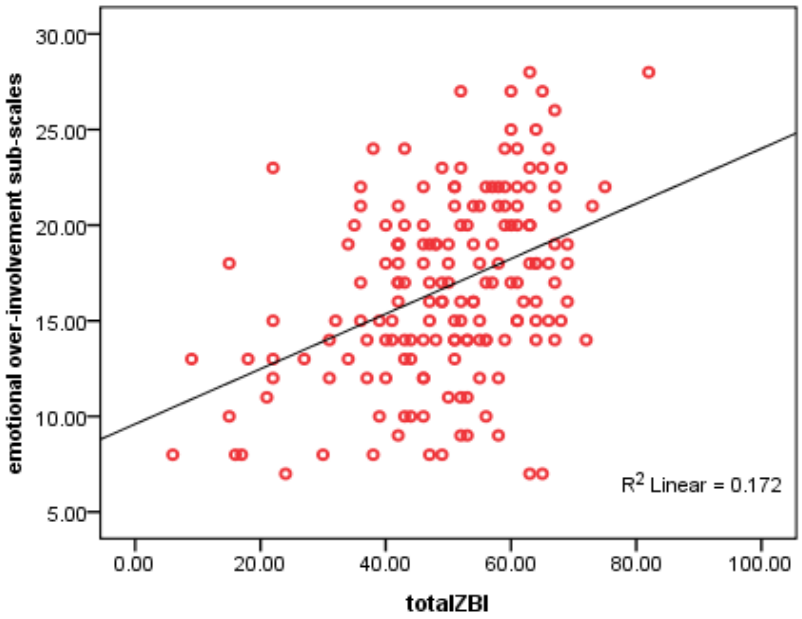

Figure 5 : The diagram of correlation between the mean score of burden experienced by the primary caregiver and the mean subscale score of emotional over-involvement in the family questionnaire

Comparison of the level of burden experienced by the primary caregivers based on their demographic characteristics:

Comparison of the mean score of burden experienced by the primary caregivers based on their gender:

The mean score of burden experienced by the caregivers was 49.6± 13.2 among male and 51.04±14.2 among female caregivers; this difference was not statistically significant (Mann Whitney U test, P=0.84).

Table 4 : The means core of burden experienced by the primary caregivers based on their gender

sex	Burden (Mean ± SD)
Male	49.6±13.2
Female	51.04±14.2

Comparison of the mean score of burden experienced by the primary caregivers based on their age:

The mean score of burden experienced by the caregivers in different age groups is shown in Table 5.

Table 5: The mean score of burden experienced by the primary caregivers based on their age

Age group (y)	Burden (Mean ± SD)
<25	45.6±1.9
25-34	49.5±2.6
35-44	51.9±1.9
45-54	52.3±6.1
>55	53.7±2.1

Comparison of the mean score of burden experienced by the caregivers in different age groups revealed that by advanced age, the mean burden experienced by the primary caregiver increased. The difference in this respect between different age groups was significant (Kruskal-Wallis test, P=0.026). Tukey's post hoc test demonstrated a significant difference

between the mean score of burden experienced by caregivers aged 45-54 years and over 55 years and that experienced by caregivers younger than 25 years.

Comparison of the mean score of burden experienced by the primary caregivers based on their level of education:

The mean scores of burden experienced by caregivers with different levels of education were compared (Table 6). The results showed that the mean score of burden experienced by the caregivers decreased by increase in their level of education; however, this correlation was not significant (Kruskal Wallis test, P=0.502).

Table 6: The mean score of burden experienced by the primary caregivers based on their level of education

Educational level	Burden (Mean ± SD)
illiterate	51.8±15.5
Elementary school	50.7±10.5
High school	48.8±13.7
College	47.2±15.6

Comparison of the mean score of burden experienced by the primary caregivers based on their marital status:

The mean scores of burden experienced by caregivers were compared in terms of their marital status (Table 7). The results showed that the highest mean score of burden was experienced by the widowed or divorced

caregivers and the difference in this respect between caregivers with different marital status was significant (Kruskal-Wallis test, P=0.024). Tukey's post hoc test revealed that the mean score of burden experienced by the married caregivers was significantly different from that experienced by the widowed and divorced group (P=0.048, mean difference:7.8, CI: 0.83 to 15.2).

Table 7: The mean score of burden experienced by the primary caregivers based on their marital status

Marital status	Burden (Mean ± SD)
Single	48.5±18.6
married	49.2±12.9
Widowed & divorced	56.8±15.1

Comparison of the mean score of burden experienced by the primary caregivers based on their occupational status:

The mean scores of burden experienced by caregivers were compared in terms of their occupational status (Table 8). The results showed that the mean score of burden experienced by the primary caregivers was not significantly different based on their occupational status and the highest burden was experienced by the unemployed caregivers (Kruskal-Wallis test, P=0.11).

Table 8: The mean score of burden experienced by the primary caregivers based on their occupational status

Employment status	Burden (Mean ± SD)
Employed	48.9±13.8
Housewife	50.4±12.5
student	47.2±15.5
retired	45.8±15.1
unemployed	58.8±21.6

Comparison of the burden experienced by the primary caregivers based on the demographic characteristics of patients:

Comparison of the mean score of burden experienced by the primary caregivers based on the gender of patients:

The mean score of burden experienced by the caregivers of male patients (51.4±13) was higher than that of caregivers of female patients (44.6± 14.8); this difference was statistically significant (Mann Whitney U test, P=0.008).

Comparison of the mean score of burden experienced by the primary caregivers based on the age of patients:

The mean score of burden experienced by the caregivers of patients in different age groups was not significantly different (Kruskal-Wallis test, P=0.52). Table 9 shows the mean score of burden experienced by the primary caregivers of patients in different age groups.

Table 9: The mean score of burden experienced by the caregivers based on the age of patients

Age groups (y)	Burden (Mean±SD)
< 25	51.6±9.9
25-34	50.1±14.2
35-44	48.1±14.1
45-54	49.3±14.1
≥ 55	51.0±17.8

Comparison of the mean score of burden experienced by the primary caregivers based on the level of education of patients:

The mean score of burden experienced by the caregivers based on the level of education of patients was compared and no significant difference was found in this regard (Kruskal Wallis test, P=0.18). Table 10 shows the mean score of burden experienced by the primary caregivers based on the level of education of patients. By increase in level of education of patients, the mean score of burden experienced by the caregivers decreased.

Table 10: The mean score of burden experienced by the caregivers based on the level of education of patients

Educational level	Mean± SD
Elementary school	51.8±13.9
High school	48.6±13.1
College	46.7±16.5

Comparison of the mean score of burden experienced by the primary caregivers based on the occupational status of patients:

The mean score of burden experienced by the caregivers based on the occupational status of patients showed a significant association between the mean score of burden and occupational status of patients (Kruskal-Wallis test, P<0.006). According to Table 11, the highest burden was experienced by the caregivers of unemployed patients. Tukey's post hoc test also revealed that this significant association was due to the difference in the mean score of burden experienced by the caregivers of unemployed and housewife patients (P=0.003, CI: 3.2 to 15.1, mean difference=9.1).

Table 11: The mean score of burden experienced by the primary caregivers based on the occupational status of patients

Employment status	Burden (Mean ± SD)
Employed	46.6±7.9
Housewife	44.8±16.4
student	48.6±7.6
retired	50.5±14.8
unemployed	54.1±11.3

Comparison of the mean score of burden experienced by the primary caregivers based on the marital status of patients:

The mean score of burden experienced by the caregivers based on the patients' marital status was compared. The mean score of caregiver burden of widowed and divorced patients was higher than that in caregivers of

single and married patients (Table 12). This difference was statistically significant (P=0.035, Kruskal-Wallis test).

Tukey's post hoc test demonstrated that the mean score of burden experienced by the caregivers of divorced and widowed patients was significantly higher than that of caregivers of married patients (P=0.04, mean difference=6.3, CI: 0.4-9.8).

Table 12: The mean score of burden experienced by the caregivers based on the marital status of patients

Marital status	Burden (Mean ± SD)
Single	48.5±20.1
married	46.7±13.7
Widowed & divorced	52.4±13.5

Comparison of the mean score of burden experienced by the primary caregivers based on the number of family members:

The results showed that the mean score of burden experienced by the primary caregivers in families with >3 members (54.3±12.1) was higher than that in families with 1-3 members (46.3±14.1)(Table 13). This difference was statistically significant (P<0.001, Mann Whitney U test).

Table 13: The mean score of burden experienced by the caregivers based on the number of family members

Family (number)	Burden (Mean ± SD)
1-3	46.3±14.1
>3	54.3±12.1

Comparison of the mean score of burden experienced by the primary caregivers based on the home ownership status:

The mean score of burden experienced by the caregivers based on the home ownership status was compared. The results showed that the mean score of burden was significantly lower in situations where the family owned their living place compared to that in renting families (Table 14)(P=0.04, Mann Whitney test).

Table 14: The mean score of burden experienced by the primary caregivers based on the home ownership status of the family

Ownership status of residential place	Burden (Mean ± SD)
owner	47.3±7.5
tenant	54.3±9.3

Comparison of the mean score of burden experienced by the primary caregivers based on the person(s) living with the patient:

The mean score of burden experienced by the caregivers was different based on the person(s) living with the patient; however, the difference in this respect was not statistically significant (P=0.503, Kruskal Wallis test). The results showed that the highest mean score belonged to caregivers of patients living with their parents followed by patients living with other relatives and their spouse or children, respectively (Table 15).

Table 15: The mean score of burden experienced by the primary caregivers based on the person(s) living with the patient

Patient lives with	Burden (Mean ± SD)
Spouse & children	47.7±14.0
parents	50.9±12.9
Other relatives	48.6±17.6

Comparison of the mean score of burden experienced by the primary caregivers based on the time the caregiver spends with the patient:

The mean score of burden experienced by the caregivers was significantly different based on the time the caregiver spends with the patient (Table 16)(P=0.001, Kruskal-Wallis test). The results of Tukey's post hoc test demonstrated that this difference was significant between caregivers spending more than 12 hours/day with the patient and those spending 6-12 hours (P=0.031, mean difference:8.4, CI:0.6-16.1) or less than 6 hours/day with patients (P=0.001, mean difference:11.4, CI:3.8-18.9).

Table 16: The mean score of burden experienced by the primary caregivers based on the time the caregiver spends with the patient

Time that caregivers spend with patients/day (h)	Burden (Mean ± SD)
<6	47.2±13.2
6-12	50.1±15.2
>12	58.6±6.8

Comparison of the mean score of burden experienced by the primary caregivers based on the level of income of the family:

Table 17 shows the mean score of burden experienced by the caregivers based on the level of income of the family. The mean score of burden experienced by the caregivers of patients in low-income families was significantly higher than that in higher income families (P<0.001, Kruskal-Wallis test).

Table 17: The mean score of burden experienced by the primary caregivers based on the level of income of the family

Average income of family/month (Rials)	Burden (Mean ± SD)
<2,500,000	65.4±4.9
2,500,000-5,000,000	62.5±9.5
5,000,000-7,500,000	50.5±14.1
7,500,000-10,000,000	46.6±12.9

The results of Tukey's post hoc test revealed significant differences in this regard between families with 7500,000-10,000,000 Rials and those with 2,500,000-5,000,000 Rials monthly income (P=0.001, mean difference: 15.9, CI: 7.2-24.6) and also with families with less than 2,500,000 Rials monthly income (P=0.009, mean difference=18.7, CI: 3.5-13.9).

The correlation of burden experienced by the caregivers and duration of disease:

The results showed that a significant, direct correlation existed between the burden experienced by the caregivers and duration of disease (P<0.01, Spearman's rho: r=0.4). By increased duration of disease, the level of burden experienced by the caregivers increased as well (Figure 6).

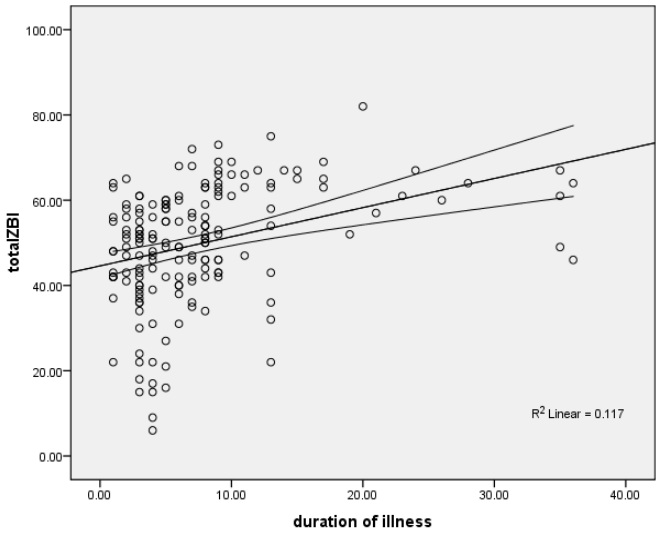

Figure 6: The correlation between the burdens experienced by the caregivers and duration of disease

Discussion

By creating a positive attitude towards changing the place of treatment of patients with severe psychotic disorders like schizophrenia from psychiatric hospitals to the society in the recent years, families of these patients are now their primary caregivers (6). This trend is growing fast in Iran as well and the family members are usually in charge of caring for patients with schizophrenia after their discharge from the hospital (7). This study sought to assess the level of burden experienced by the primary caregivers and evaluated its correlation with expressed emotion in the family, some demographic factors of the patients and family and duration of disease.

Findings regarding the burden experienced by the primary caregivers:

The results showed that the level of burden experienced by the majority of primary caregivers of patients with schizophrenia was moderate to severe and caregivers experiencing moderate to severe burden had the highest frequency. These results are in accord with those of Navidian et al. (7). They reported that the burden experienced by 73% of caregivers was above the average and by advanced age of patients, the burden experienced by the caregivers increased. Jenkins and Schumacher (1999) reported that the burden experienced by the relatives of psychiatric patients was significant (28). In another study, Perlic et al. (1999) reported that most relatives caring for schizophrenic patients experienced burnout due to disease burden as the result of signs and symptoms and dysfunction of these patients (41). Evidence shows that the level of burden experienced by the families of schizophrenic patients is similar to that experienced by the

families of patients with neurological diseases such as Alzheimer's disease or physical diseases like diabetes mellitus or cancer.

Findings regarding the emotional expression of primary caregivers:

Our results using the family questionnaire revealed that in both of the subscales the majority of understudy families had emotional expression higher than the cutoff points. In the past 50 years, researchers have developed an increasing interest in the role of social and environmental factors in occurrence and relapse of mental disorders. A considerable portion of these researches have focused on the concept of emotional expression (24). Emotional expression reflects the quality of the relationship of family members with patients and is measured by five variables indicating the attitude of patient's relatives. These variables include critical comments, hostility, emotional over-involvement, positive comments and warmth. Relatives are considered as having high emotional expression if they give negative comments about the behaviors or characteristics of patients, act with hostility (criticize or reject the patients) or are emotionally over-involved with the patient. It means that they show severe emotional responses or extreme self-sacrificing behaviors and have too much sympathy for the patient (20). Miklowitz et al. (2003) reported that educating patients with severe mental disorders and their families can significantly decrease the severity of symptoms, the relapse rate and consequently the burden of disease (42).

Family is the first institution of the society and plays a key role in diagnosis and treatment of mental disorders. Thus, a chronic disease is an inter-

personal, social and cultural concept and not only the patient's experience. Occurrence of a disease disturbs the vital balance of the family system in terms of boundaries, roles, expectations, hopes and dreams. Thus, the role of family system in disease cannot be disregarded; because otherwise, the family will be against the treatment and the medical team with the denials, pre-judgments, shames and ambivalence (43).

Findings regarding the burden experienced by the primary caregivers and the results of family questionnaire:

The results showed that the scores obtained in the two subscales of critical comments and emotional over-involvement had a significant, direct correlation with the burden experienced by the caregivers. In other words, in families with the higher level of expressed emotions, the burden experienced by the caregiver increased. It rejects the null hypothesis and suggests that the alternative hypothesis, "there is direct association between the expressed emotions and the burden experienced by main caregivers", may be true. This is consistent with most of (44, 45), but not all (46), studies which measures the burden experienced by the families of schizophrenic patients. Evidence shows that patients with schizophrenia coming from families with high expressed emotions have twice the risk of relapse after discharge from the hospital (18). Yan et al, (2004) demonstrated that patients with severe mental illness coming from families with high expressed emotions showed higher rate of relapse at the one year follow up compared to those coming from families with low expressed emotions (47).

One reason for high burden of disease in such families may be the higher number of relapses and the need for frequent hospitalizations. Studies indicate that stressors of patients can significantly affect the burden of disease experienced by the family (48). Patient stressors including the negative signs, aggressive behaviors, psychotic signs and symptoms, and frequent psychiatric hospitalizations are correlated with increased burden experienced by the caregivers of schizophrenic patients (48). It should be noted that in the families of schizophrenic patients, the most important factors creating the burden in the family are probably disorder related symptoms and frequent hospitalizations.

Findings regarding the comparison of burden experienced by the primary caregivers based on their demographic characteristics:

Evaluation of burden experienced by the caregivers based on their demographic characteristics revealed that the burden was higher in female, older people, lower educational level, widowed or divorced and unemployed caregivers. These results are in line with those of Navidian and Bahari. In their study, the burden experienced by the caregivers was higher in female, older age and divorced caregivers (7).

One possible explanation for higher burden experienced by female caregivers may be the several responsibilities that a female figure has in most families including housekeeping, taking care of children, being the primary caregiver of patients or the elderly in the family, and sometimes employment. All these factors can increase the responsibility and consequent tension and distress in women and increase the burden

experienced by them (49). The results also showed that the burden experienced by the divorced, widowed and the unemployed caregivers was higher; which may be attributed to the decreased social support, particularly perceived social support, in the unemployed and the widowed subjects. Studies have demonstrated that the unemployed and the divorced subjects often have a lower perception of the social support in the community; this issue can increase the burden experienced by these caregivers (50, 51). Also, evidence shows that age of the caregiver is correlated with the level of burden experienced. The higher the age of caregiver, the greater the burden experienced (52-54). Level of education of the caregiver also affects the burden experienced. The lower the level of education, the greater the burden experienced (54, 55). Adeosun (2013) reported that caregivers with level of education below secondary school experienced greater burden compared to those with secondary school education or higher (56).

Comparison of the burden experienced by the primary caregivers based on the demographic characteristics of patients:

In our study, the burden experienced by caregivers of male, unemployed, divorced or widowed patients was higher than other patients.

Several studies have investigated the correlation between the burden experienced by the caregivers and demographic characteristics of patients. Mishra et al, (1992) and Morse et al. (2005) stated that the level of stress was higher among the family members of male patients (27, 57). The relatives of male schizophrenic patients reported that the existing social

supports for male patients were more deficient than for female patients (28). The wives of schizophrenic men experience greater anxiety, burnout, frustration, isolation from the society and workload alongside their household responsibilities. Their husbands' disease imposes greater caregiving, financial and social responsibilities on these women; resulting in higher caregiver burden. On the other hand, it has been reported that two factors are important in creating a personal identity in an adult: family and job (58). Employed individuals benefit from factors that can lead to their independence and create a higher level of social activity and interactions. Individuals who lose such benefits experience stress as the result of increased dependence. These factors are highlighted when the individual does not receive adequate social support (59). Experience shows that unemployed, divorced and widowed patients are among the groups with increased dependence due to their impaired social support network; thus, the burden experienced by their caregivers increases (7).

Comparison of the mean score of burden experienced by the primary caregivers based on the level of income of the family, home ownership status, number of family members, time spent by the caregiver with patient and the person living with the patient:

The results showed lower level of burden experienced by the caregiver in the following situations: patients living with their spouses or children, higher income families, families that own their living place, families with ≤ 3 members and caregivers spending less time with patients (less than 6 hours/day).

Trivedi et al. (2003) reported that when parents or siblings of the patient take care of the patient with schizophrenia, the level of burden experienced by the caregiver is higher than when the spouse or children care for the patient (29); this finding is in concord with our results.

The treatment cost imposed on the family is one problem faced with the caregivers of schizophrenic patients; especially when the patient is male and breadwinner of the family and it would be difficult for the wife to take care of the bills (57). In such circumstances, the woman starts looking for a job to make money (60). This excess burden along with the already existing family and social responsibilities further add to the burden of caring for the patient (57). Our results also demonstrated that these problems in low-income families had a more significant impact on the caregiver burden. Base on the report of national Statistic center of Iran, the average income of each family in urban areas in 2013 was 17,030,000 Rials. It seems that most of the families in this study were among the low-income families of the country (61).

Also, our study, similar to the above-mentioned investigation showed that the caregiver burden was lower in families owning their living place compared to those renting.

Some previous studies have reported that in developing countries, longer hours spent by the caregiver with the patient especially in crowded families, does not increase the caregiver burden; this finding is in contrast with the findings of studies in Western countries (62, 63). In general, caregivers must keep a balance between caring for the patient and their

work and money making (13). This problem is more significant in developing countries where social support resources are less (64); because the caregiver needs to spend more time outside, working and making money and therefore, cannot spend adequate time caring for the patient. This results in self-blame and increases the burden experienced by the caregiver. In our study, in contrast with the previous studies (62, 63), longer time spent by the caregiver with patient was found to be a predictor of greater burden experienced by the caregivers and more crowded families experienced higher burden. Thus, our findings were not in agreement with the patterns reported for non-Western countries.

The correlation of burden experienced by the primary caregiver and the duration of disease:

Our results showed that by increased duration of disease, the primary caregiver experienced greater burden. Such positive correlation has been confirmed in many previous studies (30, 56). This problem is more significant in nuclear family system and increases the burden in the family especially in seeking social support. In nuclear family system, spouses caring for the patient receive less support from outside. In the early stages of crisis and disease, many people attempt to help the patients and their family, but after a while and chronicity of disease, some limitations develop in inter-personal communications in the family and with others. On the other hand, continuation of help and support by people other than the family members becomes more difficult (60). Eventually, the family faces increasing burden, and in many cases, financial problems all alone and the

burnout syndrome develops in the family members particularly in the primary caregiver.

Conclusion

Based on the results, it is concluded that most caregivers of schizophrenic patients experience significantly high level of burnout and burden. Most of the families of these patients have high expressed emotions and a significant, direct association exists between the expressed emotions and the burden experienced. High emotional over-involvement and critical comments are associated with creation of tension in the family and in some cases can lead to increased rate of relapse and re-hospitalization.

Some demographic factors of the patient and the caregiver and also the socioeconomic status of the family can significantly affect the burden experienced by the caregiver and increase it. A significant portion of this negative impact is due the decreased social support and the consequent financial issues. Some part of this negative effect is also due to the mental disorder stigma, lack of knowledge of family members and particularly the primary caregivers about the signs and symptoms of disease and patient management in the family environment.

Limitations

One main limitation of this study was small sample size. Increasing the sample size can definitely increase the power of study and accuracy of results particularly regarding the subgroup analyses.

Another limitation of this study was conduction of study in a university affiliated mental hospital in Tehran (capital of Iran) . Thus, generalization of results to other patients in the national level must be done with caution.

Suggestions

Our results emphasize the need for further attention to the families of schizophrenic patients. High expressed emotions were seen in most families and were found to be associated with higher burden experienced by caregivers. Thus, psychological educational courses must be held for the families of these patients to enhance their knowledge about the signs and symptoms of disease, its course and process of treatment and empower them for patient management at home in order to decrease the level of burden experienced. By doing so, based on the available evidence, we may also be able to decrease the rate of relapse and re-hospitalization.

Establishment of social support networks can also help these patients and their families. By doing so, the perceived social support by the family increases and the financial issues may be obviated, at least to some extent. As the result, the burden may decrease as well.

There is positive effect of supported employment on patients with schizophrenia (65, 66). Supported employment programs, as a rehabilitative approach in schizophrenic patients, increase the frequency of patients that can access to paid work and ultimately can improve the financial ability and also consequently decrease the burden experienced in the family.

Other strategies include shifting the financial resources from the hospitalization services in the psychiatric centers towards the community sectors, improving the quality of psychosocial services and promoting the standard of care. These strategies can prevent relapse and re-hospitalization of schizophrenic and other psychotic patients and will eventually decrease the burden experienced by the primary caregivers.

Future studies with larger sample sizes and randomly selected samples are required to be performed on several centers to evaluate other influential factors on disease burden and increase the generalizability of results.

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Appendix A: Family Questionnaire (**FQ**)

Name:
Date:

This questionnaire lists different ways in which families try to cope with everyday problems. For each item please indicate how often you have reacted to the patient in this way. There is no right or wrong responses. It is best to note the first response that comes to mind. Please respond to each question, and mark only one response per question.

Questions	Never/ very rarely	Rarely	Often	Very often
1. I tend to neglect myself because of him/her	O	O	O	O
2. I have to keep asking him/her to do things	O	O	O	O
3. I often think about what is to become of him/her	O	O	O	O
4. He/she irritates me	O	O	O	O
5. I keep thinking about the reasons for his/her illness	O	O	O	O
6. I have to try not to criticize him/her	O	O	O	O
7. I can't sleep because of him/her	O	O	O	O
8. It's hard for us to agree on things	O	O	O	O
9. When something about him/her bothers me, I keep it to myself	O	O	O	O
10 He/she does not appreciate what I do for him /her	O	O	O	O
11. I regard my own needs as less important	O	O	O	O
12. He/she sometimes gets on my nerves	O	O	O	O
13. I'm very worried about him/her	O	O	O	O
14. He/she does some things out of spite	O	O	O	O
15. I thought I would become ill myself	O	O	O	O
16. When he/she constantly wants something from me, it annoys me	O	O	O	O
17. He/she is an important part of my life	O	O	O	O
18. I have to insist that he/she behave differently	O	O	O	O
19. I have given up important things in order to be able to help him/her	O	O	O	O
20. I'm often angry with him/her	O	O	O	O

Appendix B: The Zarit Burden Interview

Please circle the response the best describes how you feel.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	**Score**
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4	
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4	
5. Do you feel angry when you are around your relative?	0	1	2	3	4	
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4	
7. Are you afraid what the future holds for your relative?	0	1	2	3	4	
8. Do you feel your relative is dependent on you?	0	1	2	3	4	
9. Do you feel strained when you are around your relative?	0	1	2	3	4	
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4	
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4	
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4	

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	**Score**
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4	
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4	
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4	
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4	
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4	
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
20. Do you feel you should be doing more for your relative?	0	1	2	3	4	
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4	
Total Score (out of 88)						